

Dementia and Aggressive/Abusive Behavior Summit

Summary of Proceedings

June 4-5, 2002

**Wisconsin Department of Health and Family Services
Division of Disability and Elder Services
Bureau of Aging and Long-Term Care Resources**

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Introduction and Acknowledgements

In Wisconsin last year, a man with middle-stage dementia was jailed for three days on battery charges for domestic violence, pursuant to Wisconsin's Mandatory Arrest Law (Sec. 968.075, Wis. Statute). This man was processed as a batterer, arrested, and subsequently released onto the streets without notifying his family. He was later apprehended trying to break into a red car that he believed was his. Unfortunately, this is not a unique community response to persons with dementia displaying behavioral crises. County agencies and Alzheimer's Association chapters report people with dementia being taken to jail in handcuffs, appearing in court wearing shackles, and being heavily sedated in locked psychiatric units.

Complicating this problem of appropriately addressing behavioral crises, there are three separate intervention systems operating in the state: elder abuse, domestic violence and dementia care. Each system views and treats the "aggressive" person differently. In fact, some interventions are harmful to the person with dementia in crisis and/or to their caregiver. There is a need to blend the three systems' approaches to adequately address complexities of dementia, aggressive behavior, and family dynamics.

In order to address this need, the Wisconsin Bureau of Aging and Long-Term Care Resources (BALTCR) convened a "Summit" in Madison, Wisconsin on June 4-5, 2002 of approximately 40 national and Wisconsin experts from elder abuse, domestic violence, dementia care, and related fields. Their mandate: using four case studies as a basis of discussion, begin developing a ground-breaking synthesis of what can be done in situations involving both a person with Alzheimer's disease and aggressive or abusive behavior (either on their part or on their caregiver's).

This report summarizes those thirteen hours of discussion and small group work. It also contains the background materials developed for the Summit participants' use and other documents that were identified during the process as being of particular relevance. Loree Cook-Daniels facilitated the summit. She and Michael Munson prepared the background papers and the first draft of this report.

This project was funded in part by a three-year Alzheimer's Disease Demonstration Grant from the U.S. Administration on Aging and through a grant from the Helen Bader Foundation. Funds to support Dr. Tony Braus's participation were provided by the Wisconsin Coalition on Mental Health, Substance Abuse & Aging. In addition, many of the Summit participants donated their time and expertise to this project. (A list of Summit participants and their principle fields of expertise is included as Appendix B.) We are very grateful to all who contributed to this cutting edge work.

The Summit Process and These Proceedings

The Summit was designed to bring together individuals from a wide range of disciplines and multiple systems – dementia care, family caregiving, elder abuse, adult protective services, family violence, trauma, medical systems, criminal justice, etc. – who could find themselves interacting with a person with dementia in crisis.

Forty participants were chosen to participate in two groups. Seated at the central table were approximately a dozen nationally and locally recognized experts representing each main system or discipline. Surrounding this table were Wisconsin professionals from all systems and disciplines and from throughout the state. These “observers” brought additional ideas, questions, and debate to the main table’s discussions.

Prior to the Dementia and Aggressive/Abusive Behavior Summit, all participants were supplied with background materials that highlighted the viewpoints of and research from the varied approaches and disciplines and gave information on the Alzheimer’s* disease process. (These background materials are included in the appendices.)

****Note: Because the term “dementia” encompasses many types of potentially reversible as well as non-reversible causes or disease processes, the Summit was designed to look at the issues occurring specifically for people with Alzheimer’s disease, which is the most prevalent type of dementia.***

The Summit itself began with an overview of the Alzheimer’s disease process. This presentation is summarized in the next section of these Proceedings.

Once the participants had this common understanding, they moved on to in-depth discussions of four case studies. In reporting these discussions, we have summarized the main points and developed three types of text boxes to call attention to “best practice issues;” “key concepts;” and “questions, tensions, and barriers” that warrant further consideration.

During the discussions, system issues were tracked on a separate list as they were identified. This list is included in these Proceedings. Near the end of the Summit, participants voted on which ones they most wanted to focus on in the remaining time. Seven topics were chosen and explored by small groups. These groups then shared their key ideas for addressing each issue with the full group; summaries are included here as well.

Throughout the Summit a flipchart was kept in the back of the meeting room so that participants could post questions, concerns, and comments that they wanted others to see. Nearly all of these statements were incorporated into these *Proceedings* in “Participant Bulletin Board Comment” boxes.

Alzheimer's Disease Overview¹

The summit began with an overview of the disease process of Alzheimer's.

Alzheimer's disease is a progressive illness that causes deterioration of the brain. It usually progresses slowly over many years, and causes a decline in function where the person who is affected eventually loses the ability to learn, to comprehend the present, and to care for him/herself.

The disease process is actually intimately related to how we, as human beings, learn. To understand Alzheimer's disease, the group heard about a person's brain over time.

How the Brain Works: An Overview

Think about a baby, Joe, in his mother's womb. As his brain develops, the nerve cells begin forming into clusters which each start to specialize in different tasks, such as eyesight, hearing, etc. As Joe's brain begins to form connections between its clusters and parts of the body, nerve pathways of communication are established. As the nerve pathways become more "worn in," clusters that are specific to the signaling body part develop strongly, and the others simply stop reacting.

This is where the "use it or lose it" phenomena first begins. The phrase describes how skills developed and used over time are retained, while skills not used tend to die off.

When Joe is born, his brain is still forming connections between his brain and his body. He begins developing skills such as language and eating. He also forms a concept of what it's like to be taken care of. This is his first notion of caregiving.

As he becomes an older child, he learns more skills: math, reading, how relationships work. The new skills build off of the previous clusters and pathways. While this is happening, pathways are getting so well traveled that they become automatic, like learning to ride a bike. This is a primary way we learn: by building on prior skills, prior learning. The more these pathways are used for multiple skills, the more **ingrained** they become.

Joe also forms more layers of experience with caregivers, enhancing his ideas of what it's like to be cared for. He may even have a younger sibling or friend that he begins to mentor. As an adult, Joe becomes a parent and learns about caregiving from a different perspective.

¹ Cathy Kehoe, Alzheimer's Service Developer for the Wisconsin Bureau of Aging and Long-Term Care Resources, prepared and presented the information in this section, and wrote the summary of it.

Beyond the **ingrained** memory Joe develops, there is another way he learns. It happens automatically when we are in certain kinds of situations. It's called forming a **holographic*** type of memory. This happens when we have an experience that is so intense that it goes immediately into long-term memory and is stored like a

? Key Concept ?

A holographic type of memory is formed when an experience is very intense and involves many emotions (positive and/or negative). Because these memories involve so many senses and emotions, they are stored all over the brain and have multiple connections. They are also reinforced over time as they are recalled. Common examples in our culture are "Where were you on September 11, 2001?" and "What were you doing when Kennedy was shot?"

hologram, with all of the sensations and emotions of the experience. Experiences that involve all of our senses, combined with a situation that is out of the ordinary, and having very intense emotions, are holographic. Whether those emotions are positive or negative, the memory gets simultaneously stored in multiple places in the brain (such as those related to eyesight, hearing, smells, emotions), and multiple connections are made between clusters. These memories are then reinforced over time as we review the memory. Examples of holographic memories may be your first kiss, the first time you rode a bike, or significant world events such as what happened on September 11, 2001. These could be fond memories like a holiday ritual, or traumatic things that we try not to think about. The key to holographic memory is that it can be triggered by something – a smell, a song, a person, picture or place, and you are suddenly back in that time remembering the essence of what occurred.

Joe grows old. He's beginning to get Alzheimer's disease, which is caused when plaque forms in the brain between nerve cells, and the immune system reacts to it as a foreign object, like a splinter. The body begins to protect itself against that "splinter," causing swelling around the area. Eventually, the swelling kills the brain cells in that area. The brain cells around that area develop the hallmark "plaques and tangles" that are seen upon autopsy of brains with Alzheimer's disease.

As the scar tissue accumulates, it slowly starts to impair the pathways in Joe's brain and restricts access to the skills to which he used to have easy access. The hippocampus area of the brain, which translates the present into long-term memory, is the first area to be affected. As the disease progresses, it eventually renders Joe unable to learn or retain things in the present.

*(*Note: researchers into the role of the brain in human performance originally developed this term. Researchers would train Olympic athletes to implant in their brains the experience of a perfect performance by visualizing the experience holographically – with all of the senses and emotions - before physically attempting it, thus creating a **holographic memory** in the brain which resulted in improved performance.)*

The higher levels of learning are lost first. These are the connections that have been least reinforced over the decades, or learned most recently. As more and more of the brain begin to be affected by the plaques and tangles, more and more areas of what was previously learned become lost. Yet holographic memories tend to remain, because they are stored in so many places that the scar tissue doesn't reach it all.

Humans – Hardwired to be “Parenting” Type Caregivers

Like Joe's, most people's experiences with caregiving have centered on children being cared for by adults. In child-adult caregiving, the caregiver learns how to support and mentor the child in developing new skills, learning about the world and mastering the environment. In other words, classic caregivers reinforce learning.

The problems start when classic caregiving skills don't work with people who have Alzheimer's disease because their brains physically aren't capable of new learning. To compound confusion for caregivers, the person with Alzheimer's still has access to a lifetime of past memories, which can be recalled in detail – particularly if they are holographic memories. Caregivers can't understand why their loved ones can live in the past, but not in the present. Using the parenting approach when caregiving for someone with Alzheimer's disease can therefore lead to a great deal of frustration. (See Appendix H for a comparison of Alzheimer's disease caregiving and parenting approaches.) Thus, caregivers need to learn new skills to adapt to the care needs of the person with Alzheimer's disease as the illness progresses.

Perhaps the most important point to keep in mind when working with people who have Alzheimer's disease is the ability to trigger holographic memories from the past. Past fond memories can improve Joe's quality of life when he re-experiences precious times. However, reminding Joe of traumas from his past (such as a beloved person long dead that he thinks is still alive) could trigger the original trauma of loss all over again. For instance, an elder may not be able to recognize a family member by name or relationship, but she may be able to access the emotional and sensory memory that this is someone she loves. In this same way, memories of traumas may be recalled as the result of mundane triggers.

Introduction to Case Studies

To provide a focus for our discussions, the Summit was structured around four case studies. Each case study took progressively less time to discuss, as they were designed to build on each other (in other words, approaches and strategies used in earlier cases were presumed to be considered in later cases, as well, so we tried to focus only on the ingredients in a given case study that we hadn't discussed previously). Even with this narrowing, figuring out where to start in these situations was daunting. Each one represented at least one relationship, and oftentimes many, with a history that could be decades long. Dementia was never the sole issue, nor was aggression or abuse. Instead, each scenario held multiple clues to not only what may be happening "today," but also what may have happened years and years ago. Figuring out what to look at first was as difficult as trying to figure out what sense to make of which clues.

Not surprisingly, therefore, the Summit participants' comments were recursive, going over old ground in new ways as the discussion evolved. To make this report more readable, we have grouped ideas by topic rather than as they came up chronologically.

Case Study #1:

Intervening when an Individual with Alzheimer's Disease is in Crisis

In this scenario, Mr. Cohen and his niece from out of town have gotten into a situation in which Mr. Cohen is resisting, the police have responded, and no one seems quite sure what to do next. [See next page for full case study.]

Immediate Concerns/Responses – Assessment:

Medical Emergencies

An immediate concern in this case was for the health of both Mr. Cohen and his niece. If Mr. Cohen was thrown against a truck hard enough to damage the truck, he may be injured (one possibility that should be checked for is a subdural hematoma). The niece may have been injured in the struggle over the car door. Furthermore, the episode itself could have a medical cause. Possible medical problems for Mr. Cohen's behavior to be ruled out include: a stroke, a medication reaction, an interaction between medication and something he ate or drank at lunch, and an allergic reaction to something he ate or drank.

In general, our medical specialists felt that Emergency Medical Technicians (EMTs or paramedics) should be able to do some of this quick assessment on the spot. The rest of the medical evaluation should be done in an emergency room.

Case Number 1

Mr. Cohen

Mr. Cohen was taken out to lunch by a niece who was visiting his city on a business trip. When they returned to Mr. Cohen's home, he refused to get out of the rental car. In fact, he locked all the doors. The niece unlocked the doors and tried to get Mr. Cohen out, but he kept fighting for control of the door, at one point practically slamming her arm in it. Finally he opened the door, jumped out of the car, and started running down the street.

The niece took after him. Mr. Cohen slowed to a fast walk but would not speak to her and showed no signs of stopping. He would not turn around. Not knowing what else to do, she got out her cell phone and called 911.

That was the beginning of a two-hour nightmare. The niece was not precisely sure where they were, and since Mr. Cohen's home was near a jurisdictional line, police cars from two different departments were sent to look for them. Since the niece sounded so panicked to the 911 dispatcher, the call was rated high priority and sirens were used. When the pair was located, the police attempted to limit Mr. Cohen's ability to maneuver by pulling one police car onto the sidewalk in front of him, and another behind him.

Mr. Cohen would not stop when the police ordered him to and became combative when approached, so a police officer grabbed him and threw him up against a truck (so hard that the truck company later attempted to bill the family for damages). The police called an ambulance and Mr. Cohen was strapped to a stretcher. As one officer was charging Mr. Cohen with battery to a police officer and resisting arrest, another was interviewing the niece, who admitted that based on previous calls with Mr. Cohen and their conversation at lunch, she feared he was developing Alzheimer's. She knew of no previous incidents where Mr. Cohen had gotten into trouble, and Mr. Cohen had no police record. Mr. Cohen refused to talk to the officers. Based on this information, the police determined that they needed a placement other than jail for Mr. Cohen.

For the next two hours, as Mr. Cohen remained very agitated and strapped to the stretcher, police contacted the local psychiatric facility, an emergency room, and a crisis intervention team. All said Mr. Cohen didn't fall within the scope of their services.

Finally a mental health geriatric unit agreed to take him.

Making Connections and Advocating

One participant, noting that “dementia often means ‘disconnected,’” felt that another immediate need was for someone to connect with Mr. Cohen. Ideally, this would be someone whom he knew and trusted, but it could also be a concerned professional or volunteer. The need for an “advocate,” or a person who could connect to the niece was also voiced, particularly since she may be very distressed by what happened, and she could be the only immediate source of information about Mr. Cohen.

The role of an advocate would be to provide emotional support, handholding, and practical support during a crisis. If the person in crisis was experiencing dementia and was upset, a useful strategy would be for the advocate to provide some diversion through a calming activity. Once the person was calmer, reminiscence could be used to gather information about the individual, and the advocate would consciously seek ways to further develop rapport to help with future information gathering and communication. In addition to providing immediate assistance, a person acting, as an advocate may be able to provide more formal advocacy should the situation necessitate moving the person with dementia to an emergency room or other institution?

It was noted that this advocacy function could be crucial. In a situation like Mr. Cohen’s, if he were taken to a busy urban emergency room, practices show he would be given a low priority and might spend many hours waiting for care. He might also not be assessed thoroughly. An advocate can help prevent these negative outcomes, and can spend the wait time gathering information about the person and the person’s situation. (On the other hand, it was noted that if Mr. Cohen lived in a rural area, chances were much higher that the emergency room would simply admit him into the hospital.)

★★★ Best Practice Ideas ★★★

Assign a separate person to **connect with** and **advocate for** each person involved in a crisis situation. This individual’s job is to provide emotional and practical support for “their person” during the crisis, advocate for the person within other systems, such as emergency rooms, and begin building rapport which can help during information gathering phases of the intervention.

One system that might serve as a model for this kind of focused advocacy is the **Sexual Assault Nurse Examiner (SANE) program**. The SANE program keeps specially-trained nurses on call at all times who can respond to a sexual assault victim at the hospital or elsewhere and support her or him through the evidence-gathering procedures.

The time when Mr. Cohen is in the emergency room can be used to try to locate family members, physicians, and others who may be able to answer key questions such as: Has this type of event happened before? Do they know of anything Mr. Cohen finds calming? Is there someone whom Mr. Cohen trusts who can come to the hospital to be with him?

What Happened Just Before?

A third immediate need in this situation was to gather information that could help put Mr. Cohen's catastrophic reaction into context. As noted earlier, there could be a medical cause for his sudden unusual behavior. More likely, however, there was a behavioral antecedent to his becoming upset. Possibilities that were discussed were: Mr. Cohen did not recognize his house and was distressed at being told that it was his house; he could have been upset at the thought that the niece was leaving him; the two could have had an argument just prior; and the niece could have been abusive, exploitative, or have just told Mr. Cohen something he didn't want to hear. The niece may be able to provide information that could help determine what had happened (although, of course, she may well not tell the truth if she knew she provoked the problem). As noted earlier, the niece may also have information about what Mr. Cohen ate and drank at lunch, which could be related to the crisis.

Next Steps/Interventions Phase I:

Who Else Should be Involved?

An early question that needs to be answered is whether Mr. Cohen has a spouse, partner, roommate, close friend, or relative that needs to be notified. Mr. Cohen's doctor should also be identified and notified. The niece may have this information, or a landlord or neighbor may have it.

Who Else is Involved?

A related question is who else *is* involved. It is entirely possible that Mr. Cohen is already known to other agencies, and that these agencies may have information that will be helpful in resolving the current crisis. In some Wisconsin counties, a crisis intervention team is responding to emergencies. In this approach, a "crisis plan" has been developed for people who have experienced a mental health crisis. This plan is kept available as a resource for the team to utilize in any future crises that might arise. Such plans contain information on who is in the person's life and how to contact them, medications, strategies and plans for coping with crisis, etc. These plans are then filed with police, health care providers, and others who might be in contact with someone in crisis. In such counties, one call

?? Tensions, Barriers, and Questions ??

Is Mr. Cohen competent to make decisions?

This question was key for some of the summit participants, who felt they could not even talk to Mr. Cohen's niece without first determining if Mr. Cohen was competent and, if so, getting his permission to speak with her. Competency might also determine whether Mr. Cohen had to consent to going to the emergency room. Other participants felt that competency wasn't as much of an issue in crisis situations such as the one illustrated in this case scenario.

Can agencies release information? Related to the competency question is whether agencies that have been in contact with Mr. Cohen can release any information without his explicit consent.

could provide enormous information. In Milwaukee and Brown counties, an “Access Line” can give comprehensive information on social service programs the person has accessed.

Other entities that might have important information on Mr. Cohen include: his physician; his health care facility (e.g., hospital or medical clinic); mental health facilities; adult protective services; police department; case manager; veterans’ administration facilities; pharmacist; minister or other religious leader; and senior centers.

Where Can Mr. Cohen Spend the Night?

Mr. Cohen could be admitted to the hospital, or possibly to a mental health facility (see Appendix I for a description of Wisconsin laws allowing for protective placements). If he

★★★ Best Practice Idea ★★★

Ideally, individuals with Alzheimer’s disease, when in a behavioral crisis, should be managed in familiar surroundings (e.g., one’s home); however, that is not always possible. One alternative to a locked psychiatric unit is the option Waushara County has developed. The county has designated an adult family home (certified two beds) to serve as a “crisis stabilization facility.” This is a non-acute, non-skilled residential setting where individuals can stay for a short period of time to become “stabilized.” Staff undergo 40 hours of training in working with individuals who are in crisis and are experiencing problems.

is not admitted to one of these institutions, immediate arrangements need to be made for that night. Is he stable enough to be home alone? Is there someone who can stay with him that night? Is there a relative or friend’s home he can go to? (Several participants noted that the more quickly Mr. Cohen is allowed to be in a familiar environment, the faster he will emotionally stabilize.)

Next Steps/Interventions Phase II:

Assess Mr. Cohen’s Abilities and Wishes

It is at this point that determining Mr. Cohen’s competency is important, because if he is competent, he has the right to refuse offered services. If he is not legally competent, court proceedings need to be started so that a guardian for Mr. Cohen can be appointed to make needed decisions on his behalf.

? Key Concept ?

Assessing for Alzheimer’s disease takes time. Appointments for a full evaluation often have to be made weeks in advance. In addition, assessing someone in the midst of a crisis such as Mr. Cohen’s is not wise, because the confusion and disorientation that may come from being in crisis could influence the cognitive assessment and provide inaccurate results.

Now it is also critical to schedule and obtain a full dementia screening and diagnosis. Even if Mr. Cohen was screened before, his disease may have progressed or new problems may be influencing his level of impairment. Because the wait for an appointment may be a few weeks or more, immediate scheduling is important. At the same time, the diagnosis of a dementing disorder should not be made at the time of a crisis (e.g., a hospitalization) since the cognitive testing results may not be an accurate reflection of cognitive status. The diagnosis of dementia requires that no delirium is present when the evaluation is done.

What are Mr. Cohen's wants and desires about what should happen next? Clearly his opinions are important. If he is not able to express his opinions, evidence of his life philosophies needs to be sought. Such evidence may be in the form of powers of attorney, living wills, and other advance planning documents. Family members may also be able to talk about what Mr. Cohen had wanted for his later years.

★★★ **Best Practice Idea** ★★★

Wisconsin's Health and Family Services Code 34 permits the certification (and reimbursement) of county **emergency mental health service programs** that meet certain criteria. There must be a plan for coordinated services that includes such things as specifying where short-term hospitalization is available; how a community needs assessment led to the choice of specified walk-in and mobile services hours; how linkage and coordination (including follow-up, aftercare, and follow-along) services will be provided; how the mental health needs of children, adolescents, and their families will be met; what the policies will be around assessment, response planning (an initial plan of care for up to five days), and crisis planning (a more elaborate plan for up to six months); and how client satisfaction will be measured and used as a basis for service improvements.

There are reportedly **20 counties** with such programs currently in place, and more are working on developing theirs. These systems may prove very helpful in assessing clients known to have dementia who are in a behavioral crisis like Mr. Cohen's.

A current assessment of Mr. Cohen's strengths and weaknesses (one Summit participant uses a Life Strengths Inventory), his personality style, and his usual ways of coping should be made. Interviews of friends and neighbors about the past few weeks may shed light on Mr. Cohen's baseline functioning. An occupational therapist or other qualified professional can assess Mr. Cohen's abilities to safely live alone or with others, identify risks, and outline ways of monitoring his functioning over time. There are many assessment tools that can be used to assess home safety for people with dementia.

Assess Mr. Cohen's Network

An assessment of Mr. Cohen's social support network would determine who they are and what they are capable of and willing to do – and what they need for training. These people, one Summit participant said, include not only the minister and the

neighbors, but also the grocery delivery person and the postal carrier. Such informal support people are often very open to learning about the course of the disease and, especially, productive ways of interacting with someone who has Alzheimer's disease.

Locate Services

Learning what financial and health insurance resources Mr. Cohen has will help in determining which services he may be eligible for, or able to pay for.

There is a vast array of services that may be able to help Mr. Cohen. In-home health care, housekeeping assistance, private duty nurses, adult day care, home-delivered meals, transportation, and assisted living programs are some of the many options that can be considered. Household modifications can be made to make his environment safer. Emotional supports can be set up for Mr. Cohen such as enrolling him in an Alzheimer's support group, finding him a peer counselor, or hooking him up with a daily-caller service.

?? Tensions, Barriers, and Questions ??

How do we approach? In Mr. Cohen's case, one specialist in family caregiving was surprised at the suggestion that the niece could actually be an abuser and wondered, **"Do we approach her as an ally or an enemy?"** The consensus answer seemed to be, "It's not a matter of black or white, ally or enemy; trust her, but verify." However, it is important to recognize that this approach may not be the one typically used by different systems and disciplines.

One support the Summit participants were quite interested in was finding Mr. Cohen someone who will help ensure he gets to medical appointments and is assisted in following-through on other important business.

Long-Term Planning:

If Mr. Cohen has not completed advance directives and is still competent to do so, these need to be initiated. A power of attorney can be drafted to include approving releases of information under certain conditions. If he has a durable power of attorney that has not been activated yet, the required assessments can be scheduled.

He can also be enrolled in the Alzheimer's Association Safe Return program, and can begin wearing a bracelet with information on whom to contact in an emergency.

His relatives and caregivers should be linked to Alzheimer's Association resources and support groups wherever the relatives are, to provide ongoing support and information as the disease progresses.

Case Study #2:

A Person with Alzheimer's Disease who is Aggressive or Abusive to a Family Member/Caregiver

Case Number 2

Margaret and "Mr. Margaret"

Margaret attends the Older Battered Women's Group at a hospital. She started attending the support group when she was recovering from hip-replacement surgery. She and her husband have been married for 45 years and have six children. He has been abusive throughout their marriage and most of the children are abusing alcohol, prescription drugs, and/or married and divorced several times. She has two teenage grandsons that are staying with them since their mother moved out of the area two years ago. While Wisconsin is a marital property state, Margaret has never been made aware of the family assets. They were farmers for several years, moving to a community outside of Eau Claire when they could no longer milk cows. The farm was sold to two of their sons, but she isn't sure if there is still money available from that sale, either in a bank or in other assets. Her husband has developed Alzheimer's, and she is afraid that she won't be able to take care of herself or the bills if or when he is placed in a nursing home. Although he has been emotionally abusive for a very long time, recently his physical abuse has increased as his frustrations grow. She is afraid to ask him too many questions, for fear of "setting him off" again.

Immediate Concerns/Responses – Assessment:

"Do a conjoint family assessment" a therapist suggested when we began talking about Margaret and her husband. "That might be very dangerous!" was the immediate response from a domestic violence specialist.

Thus began the case discussion that many Summit participants felt led to the largest shift in how they thought about dementia and its possible interactions with domestic violence.

Domestic Violence Dynamics

As the abuse specialists proceeded to point out, there are dynamics common in families that experience domestic violence, which must be taken into account when intervening. Top among these issues is how unsafe a situation the victim may be in. Typically, abusers are very focused on controlling and having power over their victims. Any intervention that suggests that power and control might be challenged is likely to result in more abuse of the victim. Therefore, interventions must be made with the victim's

The response to a suggestion that a family meeting could be held which was made “safe” for Margaret was met with disagreement. It was noted that it would be impossible to ensure Margaret’s safety if the man we came to call “Mr. Margaret” were to retaliate later, over something that was said at the meeting which he didn’t like.

? Key Concept ?

Professional perspective and personal experience will guide initial reactions. In the Margaret case, a dementia caregiver assumed that the reason Margaret feared “setting him off” again if she asked her husband “too many questions,” was that “Mr. Margaret” got frustrated when he couldn’t find or express answers because of his dementia. That idea had not occurred to some of the family violence/abuse specialists, who assumed the reason Margaret was afraid was because her husband had always reacted poorly to questions that might threaten his power and control over the family.

Other domestic violence dynamics that advocates said we needed to keep in mind as we discussed this case included:

➤ Multiple abusers and victims: Oftentimes a family that has one abuser ends up having multiple victims. We need to ask if anyone else in the family is being abused or is abusive.

➤ Sources of self-esteem and power: Since abusers typically attack their victims’ self esteem and limit their choices, what can happen to long-term victims is that they take pride in what is

left up to them: their long-term marriages, the household they kept, etc. It may be difficult or impossible for Margaret to think of giving up these successes by leaving.

- Isolation: Typically abusers try to isolate their victims from friends, family, and other sources of support and information. It is likely that Margaret has few contacts outside the house except for her older battered women’s group. In addition, because Margaret likely has relied on her husband as her primary social contact for decades, she may find it very difficult to lose that connection by moving out.
- Substance abuse: Family violence and substance abuse frequently occur together and the adult children are substance abusers. Are either or both of the parents substance abusers?
- Sexual abuse: One of the specialists in sexual assault pointed out that in domestic violence situations that include alcohol abuse, there has often been childhood sexual abuse, as well.
- Abusers are smart and manipulative: Abusers typically blame other people and circumstances for their behavior. The group speculated on whether it might be possible, for an abuser who believed s/he was in the early stages of Alzheimer’s disease, to blame the disease as the “excuse” for being abusive.
- Escalation: It is common for domestic violence to escalate in intensity over time.

Dementia Dynamics

Alzheimer's disease has certain hallmarks that are part of the progressive disease process. One dementia specialist noted, "In the course of dementia, it's common for the person with Alzheimer's disease to become combative – even when there's no history of domestic violence." Some of the reasons why a person with Alzheimer's disease might develop aggressive symptoms include the following.

- Excess morbidity: Are there other diseases present and possibly exacerbating the symptoms of the Alzheimer's disease that are causing "Mr. Margaret" to be more physically combative? Possibilities that have been linked to this behavior in people with Alzheimer's disease are depression and cardiac issues. Pain is a major cause of someone with dementia striking out, especially when the pain is inadequately addressed or simply untreated. Even bladder infections can cause a person to act out aggressively.
- Self-protection: People with Alzheimer's disease may interpret assistance from others as being invasive or aggressive. During activities like helping with bathing or undressing, the person may strike out in what they feel is self-defense. In addition, it was pointed out that in Margaret's case, we need to consider whether *Margaret* is abusive towards her husband.

?? Tensions, Barriers, and Questions ??

Is safety the most important value? One professional noted that health professionals tend to see valuing safety and minimizing risk as "the most important thing." Yet, she said, for so many elders autonomy is more important. How might those conflicting values between professionals and clients play out in a situation such as Margaret's?
- Communication: When people with Alzheimer's disease find themselves unable to communicate their needs or wishes, it often leads to feelings of frustration that can cause them to strike out as a way of "communicating" their frustration or anger.
- Medication: Some medications can increase aggression or inhibit control. People with Alzheimer's disease should be monitored closely when using these medications.

Dementia Approach Versus Domestic Violence Approach

One of the dementia specialists described his approach to situations in which a person with dementia is aggressive: “We have a behavior. We need to find out what it means. What makes it better? What makes it worse? How long has it happened? Are there

? Key Concept ?

Approaches for intervention between systems can work at cross-purposes; care must be taken to avoid intervention conflicts in complex situations.

In the Margaret case, it was discovered that two different systems would advocate interventions in direct opposition to each other. Interventions considered appropriate for her as an Alzheimer’s caregiver would include training her to try different approaches to supporting her husband, which could minimize his problematic behavior.

In contrast, domestic violence experts indicated that victims of abuse receive messages from their abusers that imply the victim is to blame for the abuser’s behavior. For this reason, domestic violence interventions involve educating the victim that their behavior does not necessarily influence the behavior of the abuser or change the situation.

patterns? Intervals? What’s the frequency? What precipitates the behavior? Are there things to avoid? This is a symptom; what do we make of it?” Another dementia specialist continued, “Let’s say we figure out that he’s always thrown a fit when she didn’t make dinner for him and now he can’t remember whether he ate or not [so he’s aggressive more often]. The solution might be to always leave dinner on the table, so if he’s hungry, he can eat.”

This approach, the domestic violence specialists pointed out, would play right into the abuse script. Typically abusers tell their victims that if they only behaved “right”, the abuser would not have to abuse them. What domestic violence specialists try to do is hold the abuser accountable for his behavior, and empower the victim to see that she is not responsible for causing the abuse. Suggesting that Margaret might be able to adopt strategies to make “Mr. Margaret” less abusive reinforces her victimization and powerlessness.

This discussion resulted in a key “ah-ha” moment for many of the summit participants. (Dementia specialist): “Dementia changes this [domestic violence pattern]. If the person can’t remember what happened the day before, or the minute before, it changes things. There may be strategies that may be counterintuitive but could work, strategies that might work with a person who has dementia, but wouldn’t have worked in a domestic violence situation when there wasn’t any dementia. The presence of dementia changes how we think about it.”

(Family caregiver specialist): “It changes how someone removed from the situation thinks about it. It doesn’t change how people in the long-term relationship think about it.”

Caregivers as Victims of Abuse

This discussion led into the questions: given the dynamics of power and control in domestic violence, can we or should we even ask an abuse survivor to care for her now demented abuser? Or is the very nature of having to try new strategies to cope with the dementia a reinforcement of the abusive pattern she’s been in, of being held responsible for her abuser’s actions? Of course, as someone else pointed out, the reality is that abuse victims *are* caregivers. What may need to change is our approach to how interventions are done with them.

Interventions may need to focus on empowering the abuse victim as much or more so than teaching ways to manage the behavior of the person with dementia.

?? Tensions, Barriers, and Questions ??

Abuse survivors now in the caregiving role for their abuser who has dementia: How do we support them? How do we identify and support these caregivers? Are they able to adapt to the changing dynamics of the relationship? Can they cope with this role given the trauma from the past that may or may not have been addressed? What do these caregivers need and how can we reach them? This quandary may lead us to develop innovative, collaborative ways to assist dementia caregivers.

Assessing This Situation

Moving back to the specific case of Margaret and “Mr. Margaret,” there were many things participants wanted to find out.

What has been the pattern in this family? How has Margaret found meaning in her relationship over the years? What has she done and what is she doing now when her husband is physically abusive? What has kept them together? Is religion an influence on this couple?

Why have things changed? Why, after 45 years, is Margaret suddenly attending a battered women’s support group? Both partners are experiencing changes: Margaret is learning to see her situation in a new light because of her older battered women’s group, and at the same

?? Tensions, Barriers, and Questions ??

Which “lane” is this case in? One participant said that upon reflection, she was struck by how, because the Margaret case “came up on the domestic violence radar screen, it continues to be seen as domestic violence. Are there places where we need to stop and say, ‘Does this belong in more than one lane’? Do we need to create a separate lane when there are multiple components?” In response, an adult protective services worker noted that in Wisconsin, both members of this couple would likely be seen as “clients,” and would be assigned separate caseworkers.

time, “Mr. Margaret” is growing increasingly frustrated with his dementia symptoms. Usually in cases of Alzheimer’s disease, those around the person with the disease need to have more patience than usual. How are these facts influencing this couple?

What else is going on? Who, if anyone, is actively drinking or using drugs? Has there been trauma in this family? What kind, when, and to whom? What is “Mr. Margaret’s” personal abuse history, which he may be reverting to as a result of the dementia process? What level of guilt might Margaret have when thinking about leaving a husband who now has dementia? Is Margaret *only* a victim, or is she possibly also being abusive?

? Key Concept ?

The behavior we’re looking at may be new, of decades’ duration, or a combination. If it is an old relationship pattern, it will be harder to change than if it’s a new behavior. Similarly, old patterns will set the context within which new behaviors will be interpreted.

Who is caregiving for whom? Margaret is post-hip replacement. Is she physically capable of caring for her husband? Why is Margaret worried about being able to take care of *herself* if her husband is placed in a nursing home?

What ARE the financial resources? What are Margaret’s legal rights? Is she a victim of fraud? Did the professionals involved in the sale of the farm violate some kind of professional ethics or rules by not ensuring that Margaret knew the details of what was happening? What financial resources *are* available to Margaret?

What does Margaret want now?

Can Margaret even conceive of *not* being her husband’s caregiver? Does she *want* to leave her marriage? Has she been so habituated to the abuse that she can’t even conceive of how much better her life might be if she were free from the abuse? Does she just want to go to a shelter for a couple of days’ respite, then return? If she does leave, what can be done to keep her from feeling so isolated that she returns home for companionship?

?? Tensions, Barriers, and Questions ??

Who is the client? Different systems identified different “clients.” In Margaret’s case, a domestic violence agency would view her as the “client” because their focus is to work with the victim of abuse and not the abuser. Dementia specialists, however, would identify “Mr. Margaret” as the client, and focus on how to improve his life and well being. The dementia approaches do not consider family members as being “victims,” and have no provisions for this idea. How can a system be created where the needs of both or all persons in a system are addressed?

What are Margaret’s options? Margaret had hip replacement surgery. If she does choose to go to a battered women’s shelter, will the one/s available to her be able to accommodate her possible physical disabilities? Did she develop a safety plan as part of her attendance at the battered women’s group?

What is “Mr. Margaret’s” medical status? How far along is he in the Alzheimer’s disease process? What medications, if any, is he taking? Does he have other health issues that might be adding to the problems? Is he legally competent?

What does “Mr. Margaret” need?

One dementia specialist, musing over this case the next day, said she was “troubled by the thought of this man who’s just heard this devastating diagnosis of Alzheimer’s disease. How do you process that? In this situation, it’s not going to be processed with your spouse, since there is domestic violence involved. So he faces this devastation and no one is speaking for him. He needs an advocate.”

Another dementia specialist said, “Mr. Margaret is in the penalty box. He’s lost his farm and his identity. What does he think about himself? What quality of life does he have? Is there a support system for him? How can we enrich his life? It might help Margaret if he had SOME positive aspects to his life.” To which an abuse specialist responded, “Will he be a nicer guy if he has more richness in his life? No. This doesn’t stop abusers from being abusive. [Abuse happens because of how] they think about their role in that relationship and their ‘right’ to make decisions in that household. It’s how he approaches life. He feels empowered to make the decisions and enforce the rules.”

?? Tensions, Barriers, and Questions ??

CAN “Mr. Margaret” be placed somewhere? Or does his history of domestic violence and current abusiveness toward his wife signal that he might be refused residency in a group home as being too much of a risk to other residents and staff? Is he a risk to others? How do we tell?

What is going on with the other family members?

Are they safe? Are the grandparents legally the guardians of the grandchildren? What are Margaret’s relationships with other family members like? Are they supportive of her and her safety?

Who else is involved? If there are others involved have they been involved “in the system” anywhere?

? Key Concept?

Learning language is important to many people in the process. In Margaret’s case, being in a support group and learning language such as “power and control,” and hearing types and examples of abuse actually defined, probably enabled her to label as abusive some of her husband’s behaviors that she previously thought were normal or simply part of marriage. This, in turn, may have made it possible for her to consider making changes in the situation. Professionals need to learn each other’s language, as well. For instance, summit participants asked the physician participants to define what “medically cleared” meant, and what could be – and should not be – assumed when that phrase was used.

Case Study #3:

A Family Member/Caregiver is Abusive or Neglectful of a Person with Alzheimer's Disease

In this case study, a daughter is concerned that her mother is being sexually assaulted by the caregiver her brother hired.

Case Number 3

Mrs. Kaiser

Ms. Meyer is looking for help for her mother, Mrs. Kaiser, who has dementia. The dementia started two years ago. Mr. Kaiser was alive at the time. He had a stroke and they hired a caregiver to come in. The caregiver was fired by Mr. Kaiser, because there was some hint the caregiver may have sexually abused Mrs. Kaiser.

When Mr. Kaiser died, Ms. Meyer's brother held Mrs. Kaiser's Power of Attorney. He limited Ms. Meyers' access to their mother and rehired the caregiver.

Ms. Meyer has investigated the caregiver and learned that he has a 10-year-old record of sexual assault and a 5-year-old record of assault of a child. Nevertheless, her brother refuses to fire the caregiver, and, in fact, gave him full authority to hire and fire other caregivers. These other caregivers have considerable turnover. When Ms. Meyer mentioned that she liked one new caregiver, Mrs. Kaiser said, "Oh, she won't last long."

All of Ms. Meyer's photographs have disappeared from the house. When she offered to give Mrs. Kaiser another photograph of herself, Mrs. Kaiser said, "Oh, he won't like that." Mrs. Kaiser has also told her daughter, "He puts his fingers in me and it hurts. I wish he would get his hot little hands off me."

One caregiver reported to Ms. Meyer that she'd overheard the primary caregiver tell Mrs. Kaiser, "Your daughter is the source of all your problems." She said the primary caregiver ties Mrs. Kaiser's hands down when he does personal care, using the excuse that she becomes combative. Mrs. Kaiser, when asked about this, said, "It's not necessary to be tied down."

Ms. Meyer has consulted a lawyer, but he says there is no clear evidence of abuse and that because of her dementia, Mrs. Kaiser's testimony is useless. He pointed out that there is a million dollar estate at stake, and that it was not unheard of for an adult child and a caregiver he's hired to collude in draining an estate.

Immediate Concerns/Responses – Assessment:

How Fast Do We Intervene?

The discussion of this case kept returning to one central dilemma: Timing. If Mrs. Kaiser has been sexually assaulted, quick action is needed to preserve any evidence that might be used at a trial. If there is financial exploitation, quick action is also needed to prevent further misuse of her assets. On the other hand, this is a complicated situation where there are many relationships that already seem troubled; it would be easy to inflame things by jumping too soon to allegations of improprieties. Even the appearance of “knocking on the door” might increase the tension and problems within the situation.

What Should Be the Starting Assumption About the Sexual Assault Allegation?

Sexual assault experts said it was important to take Mrs. Kaiser’s allegation seriously. Sexual assault victims are frequently not believed, they said, a fact that is particularly true of older victims and people with dementia. They didn’t want her further traumatized by not being believed. On the other hand, the dementia experts explained, many people have been wrongly accused of abusing someone with dementia. It can be common for a person with dementia to feel paranoid and develop delusions about a caregiver’s motives. In some cases people with dementia have imagined the caregiver has ill intentions towards them when the caregiver is simply bathing or dressing the person. A summit participant cautioned, “When we go into cases and presume the outcome, it biases what we find. We need to be *gathering information* rather than *trying to reach a conclusion*. Let the facts tell and reveal the story.”

?? Tensions, Barriers, and Questions ??

Who supports the intervention specialists?

Although getting support for family caregivers of persons with Alzheimer’s disease is an issue many deal with, the question of who provides support for the *professionals* involved in intervening in these situations is addressed far less often. What structure should be set up to ensure those who interact with families with Alzheimer’s disease and aggressive or abusive behavior are themselves supported personally and professionally?

What Else Is Going On?

What does the restraint use signal? There’s an allegation that restraints are being used with Mrs. Kaiser. Does that mean she has behavioral issues that are complicating the picture further? Or are the restraints being used to make sexual assault easier? (Note: There are legal parameters that govern the use of restraints.)

What are the relationships between family members like? Why did Mrs. Kaiser choose her son to be her Power of Attorney? Was there undue influence? Does she know something about her daughter that we don't? Did she just choose her son because he was the oldest and/or male? Has Mrs. Kaiser discussed the allegations with her son? If not, what's held her back from doing so? What kind of relationship do

?? Tensions, Barriers, and Questions ??

Who is to be believed? In Mrs. Kaiser's case, sexual assault advocates said her story of sexual abuse must be taken seriously unless proven false. On the other hand, dementia specialists could think of many cases where someone with Alzheimer's disease had alleged sexual assault when something entirely different was going on. The prosecutor reminded the group that in this country, people are legally presumed innocent until proven guilty.

they have? What kind of relationship does Mrs. Kaiser want with her son? With her daughter? What's been the relationship between the brother and sister? Is there a history of family conflict, or is this a new development? If the son were removed as power of attorney, would the daughter be able and willing to step up to that responsibility? What's the son's side of the story?

What are the legal parameters here? Is there a guardianship involved? Should there be? Has the power of attorney been activated? Has Mrs. Kaiser been judged legally incompetent? Does she have capacity to revoke her power of attorney? What powers does the power of attorney actually grant the son?

Who else is involved? Is there a caregiver agency involved, or was this caregiver hired privately? Are there any other systems already involved in this case?

What is going on with Mrs. Kaiser's finances? Is there any evidence that the son is misappropriating Mrs. Kaiser's income or assets?

? Key Concept ?

There is a need to educate the public on the differences between various substitute decision-making tools (e.g., Powers of Attorney, Guardianships, etc.). Many people become confused about the legal definition of and responsibilities encompassed in substitute decision-making tools such as powers of attorney, guardianships, living wills, etc. Because incorrect assumptions can be made about the scope of powers legally granted, it is important to verify the documents, clarify the appointed person's responsibilities on behalf of the ward, determine the ward's wishes, and be fully informed of the implications. For example, both POAs and Guardianships can be limited to health care or finances, and they can also encompass both.

Next Steps/Interventions:

One summit participant felt strongly that a sexual assault agency should be involved early on. Even if the caregiver was not sexually abusing Mrs. Kaiser, the allegation itself could mean that there was past sexual assault or incest that was now surfacing. A trauma assessment was also suggested for Mrs. Kaiser, both to look at any trauma that might be associated with this alleged sexual assault and to assess for past traumas that may be having an influence on her current well being.

Another participant suggested that the daughter immediately take Mrs. Kaiser to an emergency room to be assessed for evidence of sexual assault. It was pointed out that the tearing and bruising that frequently occurs when older people are sexually assaulted could be evident for quite some time.

There were several ideas for addressing the sexual assault allegation. In a nursing home setting, one person said, you could do some reality testing by changing the

caregiver and/or changing the way in which care is given, testing to see if there is a difference or pattern. In the home setting, one person suggested, you might walk in and say, "I've been hearing that bathing doesn't seem to be going very well." You could offer help, "but also be there to observe and figure things out, to collect evidence of what's going on. Is this an

? Key Concept?

Past traumas may feel current for individuals with Alzheimer's disease. In a case study brought to the summit participants' attention, staff of a day health center reported that a woman with Alzheimer's disease frequently burst into tears at the center and talked about being hurt. "Help me! He hurt me, please help me!" she would cry. She trembled and talked about being struck and about "him" making her do things in bed. Upon investigation it was determined that the woman's current husband was very loving, but that her first husband had, in fact, been abusive.

unskilled caregiver who just doesn't know what to do? Or is it sexual assault?" Another suggestion was to develop a "therapeutic alliance" with each person in the situation and begin asking questions. This approach, it was pointed out, is labor intensive.

Long-Term Planning:

Is This Case Unprosecutable?

The lawyer the daughter consulted said because Mrs. Kaiser has dementia, there would be no way the caregiver could be successfully prosecuted for sexual assault. Many prosecutors and law enforcement officials do believe this, it was acknowledged, and so they will not pursue such cases. But more and more jurisdictions are learning to do "victimless prosecution" in elder abuse situations, which means building a case that does not rely on the victim's testimony. (Examples of such cases are murder

prosecutions.) Therefore, it might depend more on the area in where a victim lives than the facts of the case itself to determine whether a case like Mrs. Kaiser's would be successfully prosecuted.

Another determinant of the "prosecutability" of this case is whether there is still any physical evidence of assault, and whether that can be collected and preserved quickly enough. Again, however, this led the discussants back to their worry that moving in too quickly or aggressively in this case might end up making the situation worse.

Case Study #4:

Both the Family Member/Caregiver and the Person with Alzheimer's Disease are Aggressive

In this case study, Summit participants focused on how the additional mental illness might be playing into the couple's dynamics, and what it means when both members of a couple are abusive.

Case Number 4

The Jameses

Mr. and Mrs. James have had a stormy marriage. Mrs. James attempted suicide in the 1950s, and Mr. James, their children report, reacted angrily at the time and still seems to be angry about it. Both of the Jameses are retired professors.

Mrs. James has Alzheimer's disease and is bipolar. Mr. James has had a stroke. Although he is physically not well, he is cognitively intact.

Recently Mrs. James left after one marital fight and went to a local senior center, where she requested housing. Aging services staff found a CBRF willing to take her on a temporary basis while other options were looked into. However, Mr. James went to the CBRF and took her home. This leaving-and-returning scenario has happened three times now.

The Jameses' daughters did not witness abusive behavior when they were growing up, but they believe abuse began after they moved out, before there was Alzheimer's disease. Mrs. James also reports there was domestic violence for many years, and reports that both parties engaged in it, with "bumps and bruises" resulting.

Both Mr. and Mrs. James claim the other is the "primary aggressor."

It appears the abusive incidents are occurring more frequently. Aside from Mrs. James seeking temporary housing, all family members agree the couple has never contemplated separating.

Immediate Concerns/Responses – Assessment:

Complications of Adding the Bipolar Disorder

Many questions were raised about the effect Mrs. James's bipolar disorder might be having on the dynamics of the situation. When she is leaving either her home or the community-based residential facility (CBRF), is she in either a manic or depressive state? Is she on medications for the disorder? If so, is she taking her medications as prescribed when she's at the CBRF? (It was noted that oftentimes, it's the spouse who helps ensure medication is taken as it should be.) One of the psychiatrists said that the bipolar diagnosis might even be contributing to what others were labeling as abuse: "It's typical in families with bipolar disorder that *someone* in the family is over-controlling. Affective [emotional] expression is stifled in families with bipolar. Bipolar disorder is about dyscontrol. Mrs. James having the disorder puts her husband in the role of controller and he may, in fact, help keep her stable."

Who's the Perpetrator and Who's the Victim?

There was quite a bit of discussion about which of the Jameses was the perpetrator and which the victim. In the "primary aggressor" domestic violence concept, one person is exercising power and control over the other in an abusive way, and the victim is defending his/her self. (See Appendix E for a "Power and Control Wheel", specific to older victims, that explains the types of tactics used in domestic violence.) It was pointed out that physical abuse doesn't have to happen all the time, that victims can be controlled by a look if they've experienced previous physical assault. In addition, as elders' physical health declines and they become more frail, they may fear assault more and, indeed, the assault may hurt more than it did before because of complications like arthritis.

? Key Concept?

Questions must be phrased carefully to get accurate answers. Many elders do not describe what happens in their families as "abuse" or "domestic violence." Questions like "Do you feel safe at home?" and "Does anyone try to control whom you can see?" may elicit more accurate answers. It is especially important in sexual assault cases to talk explicitly about acts because many elders think only vaginal rape is sexual assault, or lack language to describe what happened to them.

Another participant argued that "trying to figure out who is the perpetrator and who is the victim is not useful here. Our goal is to stop the violence; the interaction between this couple isn't right, and we need to focus on that."

What's Happening “Just Before”?

Why is Mrs. James leaving now, when the abuse is long-standing? What happens just before she leaves home? Is she making a conscious decision to leave the house, or is it an impulsive act? What happens just before she comes home? Is she calling Mr. James and asking to come home, or is he seeking her out and convincing or coercing her to come home? Is her increasing frailness leading her to be more self-protective? Is Mr. James being, as one participant suggested, “pretty intrusive” by going to the CBRF, or does she invite him? One caregiver specialist noted that it’s quite common for individuals with dementia to get placed in a facility and immediately want to return home.

Another participant pointed out that a coping strategy used by victims within families with domestic violence is to try to identify the abuser’s patterns of behavior, so that they can read the behavior and predict the violence. However, a domestic violence expert disagreed, saying that abusers typically change tactics deliberately so that their victims cannot predict their reactions to any given trigger. This switching of tactics keeps the abuser in control, by surprising the victim periodically. When dementia enters the picture, however, a different kind of unpredictability can occur. The person with dementia may have behavior and mood fluctuations that are related to the progression of the illness and not to intentional power and control tactics. Being able to determine the differences between disease-based and intentional variations in behavior is something yet to be explored as an assessment strategy.

What Happened Long Ago?

Someone who has attempted suicide is at higher risk of attempting again. Mr. James is still angry at his wife’s decades-old attempt. Does this mean he has little insight into mental health problems? Could that signal he has little awareness of dementia, as well? A trauma assessment might prove useful for both Jameses; one participant recommended the approach outlined in the *Crossroads* manual (see Appendix L).

What is the Jameses’ Current Physical and Cognitive Status?

Between this couple, who is caring for whom and in what way? One participant pointed out that we don’t know for sure that Mr. James is cognitively intact, nor do we know how frail and in need of his wife’s care he is. It would be helpful to know Mrs. James’s level of dementia and her current skill level and capacity. One participant wanted to get Mrs. James a psychiatric evaluation focused specifically on her bipolar disorder.

Next Steps/Interventions:

It was noted that since Mr. James is not well, supporting Mrs. James in her possible intention to leave puts him at more risk. This was one of the reasons the James were another case in which people felt multiple advocates might be in order (plus “someone to manage the role” of the multiple advocates).

It was suggested that in-home care could help reduce the violence in this couple by breaking the isolation. By providing someone they could talk to, there would be someone to monitor the situation that could look for bruising or broken dishes, etc. If the Jameses are “sparking” each other during care activities; in-home care could also provide more buffers there, as well as just generally helping with the care needs.

A strength assessment of each of the Jameses would identify the positives they could build on. Someone asked if the daughters could be brought in to provide more help, support and information.

★ ★ ★ Best Practice Idea ★ ★ ★

Interviews always need to be done separately when the possibility of abuse in a family is present. One participant suggested that **intake forms** routinely include questions about whether one feels safe at home or is worried about a situation at home. One person suggested asking, “Do you think this person will be a good caregiver?”

Long-Term Planning:

If Mrs. James does want to leave the marriage, a safety plan should be developed with her that includes provisions for taking her needed medications. If it seems Mr. James has been interfering with Mrs. James’s intentions to leave, a restraining order for him might be needed. If Mrs. James wants to remain at home, some of the possible interventions could include:

- Using a Family Systems Model as a therapeutic approach to teach the family how to better manage their tensions;
- An anger management class* for one or both of them (assuming Mrs. James could benefit from this depending on the stage of Alzheimer’s disease she is in); (*Note: May not be appropriate in certain situations of family violence.)
- Teaching Alzheimer’s caregiving strategies for Mr. James; and
- Regular respite/time-out arrangements.

Implementation and Systems Issues Identified

Throughout the Summit, a list was kept of “systems” issues. These were defined as issues that are inherent within one or more specific systems or disciplines which could be barriers. These issues need to be worked on, in order to enhance the ability of systems to collaborate to better serve people who have multiple problems involving Alzheimer’s disease and aggression/abuse. The identified issues are listed here in the form of questions. (They follow no particular order). Also included are “**Participant Bulletin Board Comments**” which were anonymously posted in the back of the room throughout the summit.

- How do we resolve or address the differences in approaches between domestic violence and dementia caregiving?
- How do we address the use of force by law enforcement in situations with people who have the special needs of dementia?
- How do we promote inter-disciplinary learning and collaboration?
- How do we figure out who is “in the system” and who is out?
- How do we educate people on who to call first in a crisis involving dementia and abusive/aggressive behavior? Who *should* we call first? Who should be identified as first responders?
- How do we figure out who can ask what questions throughout the various stages of response (release of information during crisis, intervention, long-term planning across systems and disciplines)?
- How do we make the systems work and who should be involved? At the state level? At the county level?
- How do we find/identify and assure access to someone who can be an “advocate” to comfort the person in crisis?
- Ally versus enemy: how do we identify and approach?
- How do we resolve confidentiality issues?
- How do we pay for what we want?
- Are there better alternatives to emergency rooms for stabilizing a person with dementia in crisis?

- How do we address situations when a system says, “he/she’s not appropriate for our services?”
- How do we adapt the “Sexual Assault Nurse Examiner Model” to support people in emergency rooms with dementia crises?
- How do we help victims when they decide to permanently leave an abuser?
- How do we ensure that alternative housing for abused individuals is accessible?
- How do we access financial information when one family member needs to know it and doesn’t?
- How do we address generational resistance/stigma regarding therapy?
- How do we differentiate between domestic violence and communicative behaviors in the person with progressing dementia?
- How do we take into account and accommodate religious and cultural differences?
- How do we distinguish between abuse, self-defense, and communication?
- How do we assist people in acquiring language to name behaviors?
- How do we avoid re-victimizing a victim by asking the victim to change his/her behavior (to accommodate a former abuser who now has dementia)?
- How do we incorporate gender socialization differences in our work?
- How do we assess for alcohol and substance abuse?
- What do we do to address the law enforcement system’s interactions with persons who have Alzheimer’s disease?
- *Can* an abused caregiver *be* an effective caregiver for his/her abuser? How do we support these caregivers in their roles?
- How do we help someone with a newly diagnosed case of dementia cope?

★★★ **Best Practice Ideas** ★★★

Emergency Medical Technicians are able to perform more sophisticated interventions on the way to the emergency room as the result of being **in radio contact** with the physicians in the emergency room. This model could be adapted to dementia crisis situations.

- How do we simplify all of this complex information so that it can be used easily in crisis situations?
- How do we measure our interventions to know if they were successful?
- What are the *essentials* of what we've talked about?
- How do we train health care providers to recognize and be knowledgeable about abused caregivers?
- How do we get a family that enters through the domestic violence system into a more comprehensive system?
- Do we add another category in the abuser typology for an abuser with dementia? What would we say about this type?
- How do we balance safety and autonomy?
- What do we do when facilities refuse to take people with dementia who have a history of aggressive or combative behavior as residents?
- How do we educate the public about all forms of powers of attorney?
- How do we educate professionals about, and how to recognize, elder sexual abuse?
- Are there domestic violence coping strategies that won't work with dementia? Are there any strategies that will work?
- Should dementia programs have, and routinely use, a screening tool for victims of sexual assault, domestic violence and other forms of trauma?
- What legislation do we need to help us prevent or intervene in these situations?



Participant Bulletin Board Comments



"I wish we would have had a specific case that did not have domestic violence but rather [another] elder abuse scenario."

"Elder abuse issues are often different than domestic violence – some may have similarities, but...."

Choosing Key Issues:

Through a voting process, **summit participants chose seven of these issues to brainstorm about in small groups.** Each group had three to eight participants. A reporter from each group summarized the group's discussion for everyone at the end of the brainstorming session. The following section summarizes the results.

Small Group Work on Key Systems Issues

Key Issue #1:

If We Developed a Screening Tool on Sexual Assault and Domestic Violence for Use in Dementia Settings, What Would It Look Like/Include?

A screening tool on sexual assault/domestic violence (SA/DV) in dementia settings would be geared towards use in gero-psych clinics or by crisis response teams. This tool would only be used after the client presented with Alzheimer's or dementia symptoms.

It would be important that this screening tool cover a history of domestic violence for two primary subjects:

- 1) people who have Alzheimer's disease or dementia, and
- 2) people who care for the person with Alzheimer's/dementia.

It is also critical that this tool is not strictly limited to only sexual abuse and domestic violence, but rather is broadened to **cover a wider range of life traumas**. A life trauma could include incest, alcohol or other drug abuse (AODA) issues, childhood trauma (including abuse,

neglect, or surviving the holocaust), being a war veteran, or surviving a house fire or the death of a child. A broad definition of trauma is important, since many types of traumatic "holographic memories" can be triggered. The screening tool could be based on existing protocols, which already contain relevant questions. The screening tool should follow the general framework of asking general questions that become more specific as the interview progresses.



Participant Bulletin Board Comments



"...[W]ho is to define what is 'abusive' or 'supportive' or any value of society? In Margaret's case does *she* see her relationship as abusive or is the 'system' defining what is abusive and telling her it is so?"

Some examples of questions include:

- *What kind of work did you do during your life?* (Follow this question with ones that are more specific, which might include asking specific trauma questions.)
- *Have you ever had a life experience that you consider traumatic?* (Start with traumatic events like natural disasters; move gradually towards more personal questions about unwanted sexual experiences.)
- *Have you ever experienced physical abuse or watched others hit or strike each other?* (It is important to inquire about secondary victimization.)

- *When have you felt unsafe?*
- *Have you ever experienced any serious financial setbacks such as the “Great Depression” or financial exploitation?*
- *What is your plan for financial management?* (Ask this question of the family support system as well as person.)

The screening tool must be **adaptable** in order to assess people in different stages of dementia. As the dementia becomes more severe, tapping into the person's emotional experiences will play a more dominant role.

An effective screening tool can be used to develop a care plan. In discussing the individual's trauma(s), questions about how the person has survived, what they have tried, what has worked, etc. may play a significant role in outlining an effective care plan. Allowing reminiscing will shed light on their trauma and assist in developing a care plan. Reminiscing may also be a way for the elder to bring himself back into the present from re-experiencing/remembering his traumatic event(s). Other effective ways of helping a client shift back to the present may include techniques like holding up a mirror to allow them to see that they did survive. (**Editor's Note:** Use caution with someone in mid-late stage dementia/Alzheimer's disease because s/he may not recognize him/her self in the mirror anymore. This could be very upsetting, and produce quite negative – unintended - results!)

The development of a care plan needs to take into consideration different specialists (e.g. trauma specialists, Alzheimer's experts, physicians, care providers, etc.). Collaboration is essential for effective care plan development.

★★★ Best Practice Ideas ★★★

When a comprehensive crisis care plan has been developed, it may be helpful to file a copy of the plan with the county's emergency mental health **Crisis Response Team** (in counties where teams are operating). This can provide the team with immediate information on ways to provide effective help to the person who may experience further crises.

Some specialists may need significant additional training or cross-training. Obtaining grants or other financial incentives may encourage agencies and individuals from various disciplines to become more involved and participate in the cross-training, so that they may be better able to fulfill their role in the care plan.

Working with trauma survivors or dementia clients may not be comfortable for everyone. In the screening process, it is important to remember not to ask questions if the provider is unable to handle the answers. This is particularly the case when it would be appropriate for the provider to follow a client disclosure with a question about what the client would like the provider to do about the situation they present.

Key Issue #2:

What Do We Do to Address Law Enforcement and its Interactions with Persons Who Have Alzheimer's?

Identifying the issues, in this situation, led to some possible solutions:

Nursing homes often call law enforcement to address a resident "eloping," or facilities request that police transport clients between facilities (e.g. to or from emergency rooms or psychiatric units). Both nursing homes (and other long-term care facilities) and law enforcement need to be more aware of what requests and actions are appropriate for each situation.

Many law enforcement personnel lack the training necessary to know how to respond to situations with combative people, especially elders with dementia, so they respond with a "one size fits all" approach. Often, law enforcement officers perceive situations as more dangerous than they actually are. The development of appropriate protocols and tools could assist law enforcement in: handling combative elders; responding to allegations of abuse; working appropriately within mandatory arrest mandates; dealing with people with Alzheimer's disease as witnesses (including successful ways to interview them), and many other issues. Police also need training in recognizing that they are not always in charge and that not everyone's physical aggression is in need of being restrained/controlled.

In addition to care facilities calling in law enforcement, **people with Alzheimer's disease also call the police - sometimes inappropriately.** Some residents may have delusions, such as being poisoned by staff, or that someone is out to get them.

Police need to be more aware of how to interview people with dementia, determine if there *is* a crime, and take the appropriate action. One common pitfall is that police believe that when there is an incidence of sexual assault or other battery in a facility, that this is not their jurisdiction. They may believe that the state in its regulatory role will investigate and address these issues.

Laws also need to be clarified, especially mandatory arrest laws. Many times law enforcement officers do not perform their own investigation of a situation, perhaps not even talking directly with the elders/people with Alzheimer's disease. Additional issues of where to take people, if a mandatory arrest is deemed necessary, also must be addressed.



Participant Bulletin Board Comments



"How do you attend to the fact that people with dementia 'create uncertainty' as credible witnesses, which may require an assessment, BUT you may lose valuable time [if you do an assessment] regarding sexual assault evidence collection? How do you 'rule in' versus 'rule out'?"

Clearly, one of the main solutions is increasing the quality and consistency of training for law enforcement in dealing with people with Alzheimer's. One aspect of training needs to involve how police should perform initial investigations of alleged crimes in facilities. In initial investigations, they need to have a protocol and be trained in how to assess the situation; keep people safe and avoid retaliation; and use circumstantial, corollary and medical evidence to help build their case. Training on how to de-escalate situations, how to involve family members in acquiring history, and using the services of adult protective services to elicit information may be useful.

Another area training is needed is around the use of force with people who have dementia. Officers need to learn techniques for intervention that put the safety of the person with dementia first, including the use of techniques other than force to de-escalate and redirect the person with dementia who is agitated. Escalation of the situation may occur if the person with Alzheimer's is even simply approached by law enforcement, because the presence of an officer approaching may frighten and further agitate the individual. In this situation, police may believe they need to protect themselves, so they use force and cause the person with dementia to lash out in a perceived need for self-defense. There are very effective techniques for building rapport with and calming individuals with dementia who are agitated and/or combative. In addition, conservative techniques for physical intervention can be used which put the person's safety first.

In situations of mandatory arrest, as noted above, laws and protocols must be clarified, including offering case examples specific to situations involving elders with dementia, since current laws are not designed to protect individuals with dementia. In violent situations, police may feel the need to use force and/or remove a person involuntarily. However, it is always better to attempt to get a voluntary agreement to be taken to another location for intervention. There may also be resources available in a community to call in a third party to keep the person where they are.

Some techniques that could be implemented are **training dispatchers to help talk people through situations and possibly getting family members involved as soon as the call comes in.** Family members may have information about what types of medication the person is on, what their history of aggressive behavior is ways of calming the person and who their primary care physician is. Often family members keep this information in writing in an easily accessible place.

Each police department needs a designated expert in elder abuse that can be trained to serve as a resource. This person should be well informed on physical, sexual and financial abuse and should be trained on dementia issues as well. If a city is not large enough to designate one person as an expert in elder abuse, a sheriff or other member of a county law enforcement team could serve this role.

Key Issue #3:

How Do We Pay for What We Want?

This group first identified two key points. They noted that:

- **"A significant amount of money is needed to pay for a range of services, including competency evaluations; and**
- **There is a need for more volunteer advocates.** Consumers, clients, health care providers, law enforcement, courts, the justice system, domestic violence professionals, the Alzheimer Associations, and sexual assault professionals all desire more advocates.

Currently there are many existing sources that could be tapped into for potentially funding competency evaluations. Such sources include Medicare, Medicaid, HFS34* and private insurance companies. Long-term care insurance companies might be interested in examining interventions for crisis in order to help keep people in their homes in the community. Grants from private foundations may be useful for general funding issues, as well as in funding special projects. Social service block grants may also provide additional funds for local support.



Participant Bulletin Board Comments



"Mandatory insurance parity for mental health and/or dementia is needed to help resolve funding dilemmas and promote development of adequate resources."

Alzheimer family caregiver support programs in each county have the opportunity to determine how their funds are spent. Funding for program enhancement, expansion or start-up can last up to three years. Individuals enrolled in the program can receive funds for direct service needs up to the local annual maximum.

Maximizing the efficiency of funding is key. Handouts and brochures can also be effective in identifying key funding sources. Drug companies currently offer discount card programs, and free samples for doctors to distribute. A list of 800 numbers for obtaining the discount cards could be provided to families who cannot afford prescriptions.

* HFS34 is discussed in one the "best practices" text boxes earlier in the report (see page 15).

Currently there is no funding associated with mandates for comprehensive evaluations (Chapter 55.06, WI stats.). At present, there is no charge for evaluations, although there is a cost involved – particularly for a complete and detailed evaluation.

It is appropriate to determine if there is any way to receive funding or payment for evaluations. **Other funding sources to consider might be mental health/substance abuse programs; drug companies that often offer funding for conferences, initiatives, and/or training; and law enforcement.**

Key Issue #4:

How Do We Resolve Confidentiality Issues?

Issues of confidentiality can be approached from many angles. Most professionals have a clear understanding of the rules of confidentiality, but it is important to codify what is expected and note the applicable exceptions. One approach would be to develop a manual that multiple disciplines could contribute to and use. For example, the Department of Health and Family Services could **compile a manual that contains statutory references and professional confidentiality standards, including the institutions that are involved.** This manual could include references with a pull-out of crisis and emergency rules/protocols. A significant portion of the manual needs to address exemptions and crisis situations, since these are commonly the most challenging areas to navigate. Clear division between crisis protocols and what happens when the client is not in a crisis state need to be explicitly delineated. Dementia response teams (if operationalized) would use this manual, as well as be able to contribute to its content.

Creating a standard best practice release form would be useful for dementia response teams. Standardized forms would create a sense of security and decrease the sense of risk, providing the confidence to allow professionals to do their jobs without worry.

One key issue is that systems are not communicating well with

each other. In an ideal world, systems (e.g., doctors, pharmacies, social service agencies, aging agencies, and other providers) would be able to communicate with each other without a release.



Participant Bulletin Board Comments



“Confidentiality and access to information are key issues.

“I believe a complete legal research project regarding these issues is needed since it appears certain systems (e.g., crisis centers and VA inpatient units) feel they can obtain information.

“Then, give scenarios of who can release what to whom and when.”

The goal for many providers is to best assist their clients. Many providers err on the side of not providing information because they are concerned about confidentiality issues and the lack of a signed release form. Clearer guidelines about when a form is necessary and the circumstances when it is not necessary would better serve clients.

Key Issue #5:

How Do We Make the System Work and Who Should Be Part of It (State and Community Levels)?

Training is a key element in making systems work. All entry point staff need to have in-depth training on techniques for working with and screening people with dementia. Entry point staff would include all law enforcement (who could be trained through a state level curriculum disseminated to police departments); triage staff at crisis centers; and emergency room staff (possibly including specialists who are on call as screeners). In conjunction with training, establishing a referral list of local physicians who are experts in dementia and who would serve as consultants in emergency situations would better serve clients and entry point staff.

Similarly, selecting a lead agency to be the access point for crisis intervention may be beneficial. The lead agency's responsibilities could include: receiving crisis calls; having 24-hour on-call triage staff who could refer callers to other resources; addressing case and systems issues in concert with other agencies (e.g., hold weekly case meetings of the team, inviting experts to address specific issues); creating inter-system or agency confidentiality of information agreements to be able to share information with others; and linking people with Alzheimer's to appropriate diagnostic screening by dementia experts. A lead agency could help serve the role of access point, being able to refer to appropriate diagnostic clinics, doctors with expertise on dementia, law enforcement, APS, elder abuse, and other county-based agencies that could help serve the client. (Current lead agencies performing this function for mental health are HFS 34 "Emergency Mental health Service Programs." Perhaps these established programs could start out being the lead agencies for dementia intervention?)



Participant Bulletin Board Comments



"How do you quantify the number of older victims of domestic violence who may be/are in position to be a caregiver of an individual with dementia?"

[Another poster]: "We do need to remember that not *all* cases of dementia involve someone with domestic violence issues. What percentage of cases involve both situations?"

[Third poster]: "15% of those over 65 have dementia, but what percentage of those cases have domestic violence issues?"

Three options were discussed for crisis stabilization:

- First, develop a team that performs its own screening, in addition to law enforcement or the emergency room staff, in order to look for more complex, multi-systems issues.
- Second, establish an on-call staff team (paid or volunteer) that is trained to go into homes or facilities to stabilize clients.
- Third, establish crisis homes that are staffed with people who are familiar with Alzheimer's disease and crisis stabilization.

One suggestion was made regarding prevention. **At the time of a diagnosis with Alzheimer's, have people establish advanced directives for their care in crisis situations**, including a confidentiality release, an indication of who is allowed to access critical information about themselves, who to contact, and a power of attorney.

Key Issue #6:

How Do We Resolve/Address the Sexual Assault/Domestic Violence “Versus” Aging/Dementia Approach Differences?

A key issue in resolving and addressing the sexual assault/domestic violence (SA/DV) "versus" aging/dementia approach involves **cross-cultural communication**. There is a need for thorough understanding of each culture by the other group, to be able to move to the next level of working with each other. One place to start this type of complex understanding is through cross-training APS workers who deal with elders, as well as training caregivers directly.

One limiting factor is the language that is used in either discipline.

Words such as "caregiver" vs. "care recipient" cloud interdependent situations, as do words like "perpetrator" versus "victim". There is a need for additional categories and a richer language that doesn't dehumanize through labeling, but rather allows for individuals' complexities.



Participant Bulletin Board Comments



"I really wish we could get away from using terms like 'abuser,' 'victim,' 'perpetrator.'"

Intervening in a situation where both sexual assault and/or domestic violence and dementia are present requires more intensive intervention and follow-up. Many

individuals with dementia may have lost hope of reconciling relationships and may have cognitive issues that cloud the process of healing and resolution.

Some solutions for the gap between approaches are to facilitate local meetings and create collaborative conferences. Educating professionals and helping them see the pre-existing paradigms of other professionals with a different focus will allow all to have a more complex understanding of the issues. Training people as resources within various agencies may facilitate greater communication and understanding, as might **cross-training professionals in county agencies to serve as the "resident" expert.** When agencies are communicating with each other, they can then begin to refer to each other and place clients with the appropriate agency.

A basic component of developing solutions in this area involves **more research to gain a better understanding of the cross-cutting issues and approaches.** After a greater understanding is developed, the construction of screening tools (e.g., mutuality screenings, caregiver perception of intentionality, etc.) would be useful.

Key Issue #7:

How Do We Balance Safety and Autonomy?

Balancing safety and autonomy is a sensitive dance. **Autonomy is redefined over time.** A person may move from living in their own home, to using an electric wheelchair, to having meals brought in. **Safety is redefined all the time, as well.**

In order to allow people to make their own choices as much and as long as possible, this group suggested collaborating between systems. **Because dementia is a factor in safety and autonomy, a person with dementia may not be able to define safety or autonomy in ways that other people (e.g. social workers) would.** Since there isn't a unified stance on what might be considered safe, involving multiple sources of observers -- friends, neighbors, social workers -- will help assure that a person remains as safe and autonomous as possible.



Participant Bulletin Board Comments



"Are there some assessment variables that are a necessary part of the crisis intervention?"

"Are there some assessment variables that don't need to be part of the crisis intervention, but should be included in long-term planning?"

"Are there variables that would argue against promoting/supporting someone as a caregiver?"

Neighborhoods and communities need to be added to social services resources. Neighborhoods, even in large cities, do exist - perhaps it's a floor in an apartment building. Neighbors can create reciprocal arrangements so that the elder doesn't feel they are being watched or helped without offering anything in return. The elder could share a recipe or invite their neighbor over to watch a movie. The neighbor checks in on the elder and ensures that he or she is doing fine and getting appropriate care and attention.

Safety and autonomy are pervasive, universal dilemmas. When dementia is added to the situation, family members may try to influence how or where a person is placed and how much autonomy they have. An additional influence may be caregiver isolation if a spouse is the primary caregiver. He or she may have the need for more support and less autonomy. Another significant factor is economics and lower income status, which may create greater hardships and more difficulty in staying safe or autonomous.

An elder who has experienced abuse may experience a different sense of autonomy. Someone who has been abused has been eroded by the misuse of power. When assessing individuals who have been abused, autonomy must be redefined, taking that into consideration.

In a collaborative system, **a team would be developed of people from within the county.** Since in-person meetings are not realistic, setting up regular conference calls would be one way to maintain contact and develop materials. A team could collect and distribute a master list of phone numbers and names of key individuals within the county that could be updated every year.

The addition of faith-based systems may also prove useful, since they may have more influence in interacting with the elder, due to a shared set of beliefs and values. The sharing of world views and values may provide a connection that allows the faith community member access to different means of assessing, observing and offering advice that will be acknowledged and followed. Members from the faith community would be beneficial additions to an interdisciplinary team (I-team).



Participant Bulletin Board Comments



"Can a victim of domestic violence be a caregiver? Does it involve more than forgiveness? Does it involve more than understanding appropriate approaches?"

Another potentially useful tool would be to examine a hospice model. Hospice care reflects and recognizes that medical science "allows" people to live longer, but not necessarily better.

Summary of the Summit Experience

At the end of the Summit, facilitator Loree Cook-Daniels noted that during a long, wide-ranging, multidisciplinary discussion such as took place at the Summit, it can be difficult for participants to make sense of what, if any, progress they have made. She therefore summarized what she felt the participants had accomplished during their day and a half together.

“We did a lot of training of each other. We did public policy systems analysis and family systems analysis. We talked about different types of safety planning. We looked at a *lifetime* of issues *and* what happened at lunch. We discussed grandparents raising grandkids.

“We learned about power and control tactics. We explored dementia behavior management techniques. We learned about holographic memories. We evaluated legal advice and

prosecutorial merit. Some of us learned about things we’d never thought of, like how food poisoning might lead to a behavioral crisis.



Participant Bulletin Board Comments



“It is very important that we provide education to other systems outside of the dementia care network with the details on behaviors, why they occur, and when incompetence changes intentionality.”

“We learned new language from each others’ professions – like ‘medically cleared’ -- and the importance of teaching clients new language and concepts. We discussed what language is best to use with elders. We discussed how important it is for everyone to have someone whom they can connect with and who will be their advocate.

“We wondered how our systems could balance multiple clients. We identified *LOTS* of public and professional educating that needs to be done. We discovered a new question, ‘can a caregiver who has been abused be a good caregiver?’ We wrestled with many ethical dilemmas. We looked at the idea of society as caregiver.

“We explored the importance of recent traumas and the fact that long tendrils of trauma can reach through decades. We acknowledged that abusers have positive qualities, and that they may need help with devastating news.

“We realized that the point of entry someone has into the system can have lots to do with what does – and doesn’t – happen next. We pried apart the question whether aggression to one equals aggression to many, and asked questions about what actually is aggressive behavior.

“We talked about interactions between family members and explored some of the reasons why people may tell incorrect stories. We wrestled with uncertainty and how to live with it.

“We discussed mental health and substance abuse and how those issues interact with all the other issues we were discussing. We learned the importance of having a substance abuse expert at the table.

“We asked, ‘What does it take to get an abused person to leave, and what does she give up by doing so?’ We identified differences in systems and barriers from county to county within the state.

“We explored where time makes a difference: Things need to be done quickly if there may be crime evidence, but a dementia diagnosis should be done slowly.

“We discussed powers of attorney, their types, our assumptions, and the realities.

“We identified other systems we can borrow from, like the Sexual Assault Nurse Examiners and using radio controlled communication in a crisis.



Participant Bulletin Board Comments



“When setting up Dementia Response Teams, do not forget to ask about substance use and abuse. When present, it is a powerful influence. There are AODA (Alcohol and Other Drug Addictions) treatment providers, resources and techniques available. Please invite an AODA professional to these conversations when substance abuse is involved.”

“We wrestled with issues of confidentiality and capacity and consent.

“We identified Emergency Medical Technicians as a key player we hadn’t previously worked with. We talked about racial and cultural differences. We were introduced to the concept of parish nurses.

“We found out that what most of us thought was a fantasy – one phone number you can call to access information about lots of systems a client may be involved in – is actually a reality in at least a few places, and heard how much horror that system provokes in advocates for privacy rights and civil liberties.

“We discussed the concept of ‘responsibility’ from many angles – caregiving responsibility, responsibilities to abuse victims, and much more. We tried to balance the long-term needs of systems planners with the short-term needs of crisis interveners.

“We wondered if radios and on-call systems might work in dealing with situations involving Alzheimer’s disease and abusive or aggressive behavior. We learned about medical stabilization facilities and crisis plans and how they work. *Some* of us even learned to distinguish between Chapters 51 and 55!

“We talked about relationships, relationships, relationships. Within families, between past and present, between dementia and behavior, between different professions.

“We talked about the needs of out-of-town caregivers and caregivers of their abusers.

“Some of us learned how long it takes to get a formal Alzheimer’s disease evaluation.

“We discussed interventions like Safe Return.

“We challenged ourselves, ‘How will we know when we are successful?’



Participant Bulletin Board Comments



“Is caregiving stress and style much different in cultures where the parenting system is much different, such as Sweden where physical discipline of children is ‘outlawed’?

“Is caregiving stress much different in cultures where the life philosophy is much different than the western culture of individuality? Say, Taoism/Buddhism or Islam?”

“And we talked about the importance of caring for the caregivers. Please turn to the person you’ve been sitting next to for two days and tell them one thing they said or brought to the summit that you appreciate.”

Appendices

- A. Summit Agenda
- B. Summit Participant Roster
- C. Background Paper
- D. How Three Different Systems View “Aggressors”
- E. Family Violence in Later Life – Power and Control Wheel
- F. Quality of Life Outcomes for People with Alzheimer’s Disease and Related Dementias – Project Summary and Example
- G. Changing Our Minds: From Parenting to Caregiving
A Mentoring Tool for Alzheimer’s Caregivers (Revised 12/02)
- H. Regulatory and Legal Background Information
- I. Care Options Available to People with Dementia in Urgent Situations
- J. Fact Sheet About Recent Changes Affecting Medicare Coverage
- K. Trauma Assessment
- L. Wisconsin Alzheimer’s Institute Affiliated Dementia Diagnostic Centers